# Experiences of people with Parkinson's disease and their views of physical activity interventions: a qualitative systematic review protocol

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This review aims to explore the experiences of people with Parkinson's diseases' (pwPD) participation in physical activity and their views of interventions designed to engage and sustain engagement. Synthesis of the best available evidence will be used to determine any gaps in the research literature and make recommendations on approaches to increase and maintain engagement in physical activity in pwPD living in a community setting. The specific objectives are to:

**Review objectives:**

Explore pwPD experiences and preference(s) for physical activity.

Explore pwPD perceptions of barriers and enablers to physical activity.

Identify, from the perspective of pwPD, the impact of support mechanisms and behavior change interventions in maintaining participation in physical activity.

## Background

Parkinson's disease (PD) is a neurodegenerative disease which primarily affects the basal ganglia, resulting in progressive movement disorders that over time, become more disabling.[1] The cardinal features of Parkinson's disease include difficulty in initiating movements (akinesia) as well as slowness and difficulty maintaining movement (bradykinesia), tremor and rigidity.[2] Together, these symptoms contribute to a significant reduction in mobility, loss of function and a reduced quality of life.[3] People with Parkinson's disease have been shown to adopt a sedentary lifestyle and reduce levels of physical activity more quickly than their healthy peers.[3,4] For example, a large study which compared the physical activity data of pwPD (n=699) to controls (n= 1,959) found that pwPD were, on average 29% less active compared to age matched controls.[3] Furthermore, Lana et al found increased age, disease severity and inability to perform activities of daily living to be predictors of physical inactivity in pwPD.[5]

There is substantial evidence to support the benefits of physical activity in pwPD,[6-11] where physical activity is defined as "any bodily movement produced by skeletal muscles that results in the expenditure of energy".[12(p127)] Physical activity is an umbrella term for the sum of all activity undertaken throughout the day and can be subdivided into leisure time physical activity (e.g. walking and swimming); non-leisure (occupational and household) and exercise (e.g. aerobic, strengthening, flexibility), which is structured and repetitive and has an objective of the improvement or maintenance of physical fitness.[12] Physical activity can be supervised, unsupervised and performed in a group or individually. People with Parkinson's disease undertaking physical activity, delivered as a supervised exercise program, tend to report better quality of life, improved ambulation, balance, strength, flexibility and cardiovascular fitness compared with those who did not exercise.[6,7,9] A criticism of much of this research is that follow up is limited to short term (3-6 months) so it is difficult to determine if physical activity is sustained long term. Results from research across a variety of populations[13-16] suggests that recidivism upon cessation of

intervention is a reality. This is likely to be the case for pwPD unless strategies for the maintenance of long-term participation in physical activity are developed.

Because physical activity is a complex and dynamic process involving an intricate series of behaviors, identification of the variables affecting uptake and sustained participation is often difficult.[17] This should begin with an appreciation of the perspectives of pwPD in terms of understanding their preferences for physical activity as wells as barriers and enablers to participation. Pentecost & Taket undertook a large study, interviewing 130 people with chronic conditions from diverse socio-demographic backgrounds; including those, who did and those who did not attend exercise services, as well as supporters of those who attended. Results identified three factors that were particularly important in influencing engagement and sustained participation in physical activity: 'exercise identity', 'support' and 'perceived benefits of attending'. Having at least one person providing different types of support was associated with higher levels of attendance.[18] Those people who valued the social and psychological benefits of attending were more likely to attend.[18] Research in pwPD by Ellis et al. identified the importance of self-efficacy, education and age as significant factors associated with increased physical activity. Respondents with high self-efficacy were more than twice as likely to engage in physical activity as those with low self-efficacy (adjusted OR=2.34, 95% CI=1.3-4.23).[19] Ellis et al identified a number of barriers to participation in physical activity, such as low outcome expectations, a lack of time and fear of falling.[20] Enabling factors which have been identified in the PD literature include provision of support via instrumental, (e.g., provision of transport and mutual participation), emotional (e.g., provision of encouragement through a variety of face-to-face and remote means), and informational mechanisms, (e.g., type of exercise that would be beneficial to their condition by health professional or fitness instructor).

Changing health behavior in terms of moving from a sedentary lifestyle to one that is physically active is both a complex and challenging process, particularly as the success of many rehabilitation programs requires both attendance at structured sessions and adherence to exercises that are to be completed un-supervised at home[21,22]. A range of behavior change interventions have been developed and studied to support this process. Whilst a variety of approaches have been used, for the purposes of this systematic review, behavior change interventions are defined as any psychology-based interventions (used alone or in combination with other interventions, such as exercise therapy) aimed directly or indirectly at behavior change with regard to level of physical activity participation or change in perceived physical function.[23]

The National Institute of Health and Clinical Care Excellence (NICE) Public Health Guidance has identified a number of elements for inclusion in an effective behavior change intervention, which includes the use of goal setting, feedback and monitoring, fostering of self-efficacy, and social support.[21]

While NICE does not recommended one specific behavior change approach, it does recommend that

it should match the service users' needs and be evaluated.[21,24] Behavior change interventions in people with long-term conditions such as Multiple Sclerosis (MS) and Rheumatoid Arthritis (RA) have been evaluated in two systematic reviews with equivocal results. Sangelaji et al concluded that after completion of a short term behavioral intervention there was a positive effect on the amount of physical activity undertaken by people with MS.[23] In contrast, Cramp et al determined that due to methodological flaws and a lack of comparison with usual care, it was not possible to conclude whether health behavior change interventions could increase physical activity in people with RA, although the number of included studies was low.[14] The effect of the addition of behavior change interventions to physical activity programs in pwPD was studied by Speelman et al who identified increased physical activity in all sub groups of pwPD (grouped by gender, activity level and disease severity). Given the varied results of the use of behavior change interventions in long term conditions, it is particularly important to develop an understanding of service users' experiences and perceptions of these interventions in order to inform which specific aspects should be incorporated into the program.[21]

Summary

Research in physical activity in PD to date has tended to focus on supervised exercise programs. The views and preferences of pwPD towards physical activity is an important aspect to consider to support long-term participation, while an appreciation of barriers and enablers to physical activity would help healthcare practitioners design physical activity programs which best meet the needs of pwPD. Behavior change interventions have been used with pwPD to promote uptake and long-term participation in physical activity. However, when designing behavior change interventions, the needs and preferences of the target audience need to be addressed to ensure that the most appropriate approach is utilized.

This systematic review will aim to identify and synthesize the best available evidence for interventions that foster pwPD's uptake and long-term participation in physical activity, and identify any gaps in the existing evidence for further investigation. A preliminary search of PROSPERO, The JBI Database of Systematic Reviews and Implementation Reports and Cochrane databases has been performed to ensure the originality of this proposed review.

## Inclusion criteria

### *Types of participants*

The review will consider studies that include people with a confirmed diagnosis of Parkinson's disease.

**Phenomena of interest**

The review will consider studies that explore experiences, preferences, barriers and enablers to physical activity in pwPD, including the use of behavioral interventions and support strategies. Behavior interventions could include goal setting, cognitive re-structuring, and motivational interviewing, while support strategies could include, facilitation of peer/ family support.

**Context**

The context for this review is a community setting

***Types of studies***

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, and action research and the qualitative component of mixed methods studies.

## Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE will be undertaken, followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English since the inception of the database will be considered for inclusion in this review. Two independent reviewers will screen abstracts and full text articles for eligibility for inclusion, and any duplicates will be removed

**The databases to be searched include**:

MEDLINE (Ovid), EMBASE (Ovid), CINAHL (EBSCO), AMED (EBSCO), Web of Sciences, SCOPUS,

The search for unpublished studies will include hand searches of reference lists of all identified article and searches using Google, CRO database, PQDT open, Open Grey, MEDNAR, Conference Papers Index. Authors will then be contacted directly to request the full papers for inclusions, where these are available.

**Initial keywords to be used will be:**

Parkinson's Disease; Parkinson's; PD; Physical activity; exercise; motor activity; exercise program*; leisure activity; walking; tai chi; swimming; yoga; experiences; preferences; views; attitudes; beliefs; participation; engagement; adherence; compliance; concordance; enablers; motivators; facilitators; barriers.

See appendix I for search strategy

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159 **Assessment of methodological quality**

160 Qualitative papers selected for retrieval will be assessed by two independent reviewers for
161 methodological validity prior to inclusion in the review. The JBI Qualitative Assessment and Review
162 Instrument (JBI-QARI) (Appendix II) will be used. JBI-QARI is a standardized critical appraisal
163 instrument from the JBI System for the Unified Management, Assessment and Review of Information
164 (JBI-SUMARI) software. Any disagreements that arise between the reviewers will be resolved through
165 discussion, or with a third reviewer.

## 166 Data extraction

167 Qualitative data will be extracted from papers included in the review, by two people independently,
168 using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted will include
169 specific details about the interventions, populations, study methods and outcomes of significance to the
170 review question and specific objectives. Authors of primary studies will be contacted as required for
171 missing information or to clarify unclear data

## 172 Data synthesis

173 Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the
174 aggregation or synthesis of findings to generate a set of statements that represent that aggregation,
175 through assembling the findings rated according to their quality, and categorizing these findings on the
176 basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to
177 produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-
178 based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

## 179 Conflicts of interest

180 There a no conflicts of interest for any of the authors.

## 181 Acknowledgements

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## Appendix I

Search Strategy

Parkinson’s Disease OR Parkinson’s OR PD

AND

Physical activity OR exercise, OR motor activity OR exercise program*, OR leisure activity, OR walking OR tai chi OR swimming OR yoga

AND

Experiences, OR preferences, OR views, OR attitudes, OR beliefs OR participation OR engagement OR adherence OR compliance OR concordance OR enablers, OR motivators, OR facilitators, OR barriers

## Appendix II: appraisal instruments

### QARI appraisal instrument

## JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

| | Yes | No | Unclear | Not Applicable |
|---|---|---|---|---|
| 1. Is there congruity between the stated philosophical perspective and the research methodology? | ☐ | ☐ | ☐ | ☐ |
| 2. Is there congruity between the research methodology and the research question or objectives? | ☐ | ☐ | ☐ | ☐ |
| 3. Is there congruity between the research methodology and the methods used to collect data? | ☐ | ☐ | ☐ | ☐ |
| 4. Is there congruity between the research methodology and the representation and analysis of data? | ☐ | ☐ | ☐ | ☐ |
| 5. Is there congruity between the research methodology and the interpretation of results? | ☐ | ☐ | ☐ | ☐ |
| 6. Is there a statement locating the researcher culturally or theoretically? | ☐ | ☐ | ☐ | ☐ |
| 7. Is the influence of the researcher on the research, and vice- versa, addressed? | ☐ | ☐ | ☐ | ☐ |
| 8. Are participants, and their voices, adequately represented? | ☐ | ☐ | ☐ | ☐ |
| 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? | ☐ | ☐ | ☐ | ☐ |
| 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? | ☐ | ☐ | ☐ | ☐ |

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

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260 Appendix III: Data extraction instruments

261 **QARI data extraction instrument**

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

**Study Description**

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

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| Findings | Illustration from Publication (page number) | Evidence | | |
|---|---|---|---|---|
| | | Unequivocal | Credible | Unsupported |
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Extraction of findings complete Yes ☐ No ☐

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